

PHOENIX EMA RYAN WHITE TITLE I HIV Health Services Planning Council

Needs Assessment of ‘Aged’ (45 years+) Persons Living with HIV/AIDS in Maricopa and Pinal Counties, Arizona

2007 REPORT OF FINDINGS

Prepared by



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2007 ‘Aged’ (45 years+) Needs Assessment

Phoenix EMA HIV Health Services Planning Council

March 2007

Executive Summary

A person is considered ‘aged’ for domestic/United States epidemiological purposes if they are 45 years of age or older and for international/global AIDS if they are 50 years of age or older. This terminology reflects the historical nature of HIV disease in which a diagnosis was considered terminal.

Increasingly, as the population ages worldwide, this definition appears outdated. This study attempts to define the baseline of aged for the 2-county Phoenix, Arizona EMA, and describe the nature of this subgroup with distinction of where it is similar and where it differs from that of the general PLWH/A community. The study is limited to ‘In Care’ since a separate study is assessing the ‘Out of Care’ population. Hypotheses prior to conducting the study about the ‘aged’ subgroup conjectured the existence of two distinct subsets within this severe need group—a small cohort of newly diagnosed, many of whom did not perceive they were at risk of contracting HIV and were subsequently diagnosed late; and a larger cohort of long-term (15 years or longer) survivors. Long-term survivors were characterized as resistant to antiretroviral therapy, with a tendency to self-manage their disease.

The 2006/2007 ‘Aged’ In Care Needs Assessment surveyed 61 PLWHA over 45 years of age in the Phoenix EMA whose top expressed needs for HIV-related services evidence a mix of essential and supportive services including: 1) Medication 2) Primary Medical Care 3) Housing 4) Counseling and 5) Transportation and 5) Alternative and Complementary Therapies.

Service barriers evidence difficulty and/or perceived inability to access basic services including transportation and housing (#1 and 2), followed by more sophisticated clinical needs including specialty medical care and medications other than HIV meds that relate to the extensive co-morbidities reported by this subgroup.

Service gaps reported were (1) dental care followed by financially related needs such as (2) financial assistance, and (3) legal help and job counseling and (4) housing and (5) transportation. These barriers to services create challenges in facilitating entry into and retention in HIV primary medical care for the growing numbers of ‘Aged’ (45 years+) persons living with HIV/AIDS in the Phoenix Title I EMA.

2007 ‘Aged’ (45 years+) In Care NEED, USE, GAP, & BARRIER MATRIX

SERVICE	USE	NEED	BARRIER	GAP
HIV Medications	2	1		
Other Medications	3	2	4	
Primary Medical Care	1	3		
Job Counseling		4	5	3
Housing		5	2	4
Transportation	4		1	5
Mental Health Counseling	5			
Dental				1
Specialty Medical Care			3	
Financial Assistance				2
Legal help				3

Challenges the Special Population of ‘Aged’ (45 years+) PLWHA Present to the Service Delivery System

Today, ‘Aged’ (45 years+) continue to experience significant rates of diabetes, mental health disorders, cardiovascular disease, pneumonia, influenza, and injuries. Over half of the group (30 individuals) report more than 3 comorbid conditions, with half (28/56) qualifying as disabled due to their HIV disease. Over a third (22/56=39%) are Anglo MSM, almost 30% (16/56 = 29%) are women of whom 2 are substance abusers and 6 are injection drug users (remainder high-risk heterosexual); 10/56 (18%) are Anglo heterosexual males, and 8 are African American MSM (14%).

Of the 56 participants, 21 or 38% work part time, 28 or half are legally disabled due to their HIV disease and the remaining 8 are pursuing disabled status. Despite housing being reported as the #2 barrier and #4 gap; all but two of the 56 individuals (96%) reported stable housing. The two who reported unstable housing conditions reported an episode of homelessness within the past year.

Of particular note for this population which is rapidly expanding as the general population ages, is the recurrent theme of HIV/AIDS as a secondary health issue to other comorbidities related to aging. Most seemed satisfied with medical coverage and were vigilant about routine checks regarding their HIV status. Long-term survivors (over 15 years diagnosed with HIV or diagnosed before 1992) are a significant subset among the largest group, Anglo MSM. This subset consists of 22 individuals with 17 or 75% of the subgroup self-managing their care or 30% (17/56) of the entire respondent pool. They reported similar themes as the 8 African-American MSM diagnosed later in their disease state—profound distrust of HIV medications, ability or perception of ability to self manage their care, and disdain for a ‘dependence’ system of HIV case management. Eighty percent (18/22) of this largest subgroup have professional backgrounds and believe that they understand navigation of the care system as well or better than case managers currently working in the system. Other service needs reported by the entire group relate to the needs of aging individuals—financial security; long-term care including legal, financial assistance and higher prioritization of ‘other medications’, and home health care and hospice as desired services to maintain ‘in care’ status.

In addition to service needs, the isolation of older individuals, compounded by their HIV disease, concerns this group. Dominant issues are the ability to find companionship later in life and concerns about the stigma attached to their HIV disease. This concern crosses over to a prevention for positives issue since the average lag between initial concerns about their health prior to an HIV diagnosis for the ‘Aged’ respondents diagnosed after 1995 (30/56 = 54%), was eighteen months. Provider disinclination to suspect HIV or even healthy sexual practice was perceived by all 30 individuals to play a role in late diagnosis, poorer health outcomes and inability or unwillingness to discuss sex. Considerable discussion occurred about the ability of ‘Aged’ PLWH/A to work part-time and still qualify for benefits. This calculus is an ongoing debate for this age group, with intensification of the discussion as they near the age where they can qualify for Medicare.

Based upon the current needs assessment data and relevant literature, this special population requires providers to overcome existing barriers to testing/counseling, perception of sexual practice and successful entry into, engagement with, and ongoing retention into HIV primary medical care. Another successful strategy for care entry is to enforce the need for HIV testing during routine medical visits to primary care physicians or medical specialists due to the high comorbid load experienced by this subgroup.

Addressing the Service GAPS in the Continuum of Care for ‘Aged’ (45 years+) PLWHA

The ‘Aged’ (45 years+) In Care survey respondents ranked the following services as “unavailable”:

1. *Dental Care services*
2. *Financial Assistance*
3. *Job Counseling*
4. *Housing*

The top ranking service GAPS (with the exception of Dental Care services) represent services needed by those facing financial and support needs essential to stabilize lives and promote successful entry into and retention in care. Greater access to employment assistance, eligibility assistance programs and facilitation of the Social Security/insurance benefits process should reduce the expressed needs for basic assistance. Addressing the gap in Dental Care services is an important primary care-related goal.

All service needs INCLUDING dental care relate to the aging process. Service needs compounded by HIV include the disabling nature of the disease and access to HIV medications.

Estimated Costs Associated with Delivering Services to ‘Aged’ (45 years+) PLWHA

Costs for care are estimated at 25% higher than the average due to later care entry, more advanced HIV disease states upon diagnosis and the multiplier of aging syndromes complicating HIV treatment. The range of \$22,500-25,000 per client per year was determined through chart review of actual costs incurred for PLWH/A over 45 years of age. Adding the cost of ‘normal’ co-morbid conditions associated with aging including diabetes, heart disease and orthopedic conditions and the complexity of medications related to these diseases, the incremental cost is \$10,000 for a total of \$32,500-35,000. The interaction of medications associated with these conditions and an HIV medication regimen further complicates complexity of care for ‘aged’ PLWH/A.

Chapter 1: Introduction

Annual Needs Assessments are studies conducted to determine priority service needs and gaps in the continuum of care for People Living with HIV/AIDS (PLWHA). Results of this client-centered activity are used to establish service priorities, document the need for specific services, determine barriers to accessing care, provide baseline data for comprehensive planning including capacity building, and help providers improve the access to and quality of services delivered, especially to the designated ‘Severe Need Groups/Special Populations’. ‘Aged’ (45 years+) are one of the populations of special concern to the Phoenix EMA HIV Services Planning Council.

A comprehensive assessment of the service needs of ‘Aged’ (45 years+) persons living with HIV/AIDS (‘Aged’ (45 years+) PLWHA) and currently In Care ¹ within the Phoenix EMA was conducted from December 2006 through February 2007. This assessment of need included an In Care written survey questionnaire of ‘Aged’ (45 years+) persons receiving Ryan White funded services utilizing the Needs Assessment Client Survey (NACS) tool.

Relevance of the Phoenix Title I EMA ‘Aged’ (45 years+) Needs Assessment Study

Trend-line. The trend line for ‘Aged’ (45 years+) shows that this subgroup comprised 38.9% of People Living With HIV/AIDS in the 2-county Phoenix EMA for the years from 2000-2004. AIDS prevalence was over twice as common as HIV prevalence (38.8% PLWA versus 18.3% PLWH).

Newly diagnosed cases mirror HIV/AIDS prevalence for this five-year timeframe, with 18.9% of the newly diagnosed consisting of people over 45, a slightly higher figure than those living with HIV; and 35% of newly diagnosed with AIDS consisting of those over 45 years of age.

Current epidemiology. The latest epidemiology figures provided by the Centers for Disease Control & Prevention (CDC) indicate that the rate of HIV and AIDS is on an upswing for the ‘Aged’ subgroup.

Incidence. For the two-year period from 2004-2005, newly diagnosed AIDS cases comprised 28% of the infected area—versus 18.9% and 35% for the five-year period from 2000-2004 for an average of 26%.

Prevalence. The last year of reporting (2005) indicates that 44% of PLWA were ‘aged’ (compared to the prior four-year period of 39%) and 35% were PLWH (compared to the prior four-year period of 18%). This increased prevalence and slightly elevated incidence demonstrates the risk of contracting HIV disease among the ‘Aged’, compounded by continued immigration of these age groups to the EMA and natural aging of the resident population.

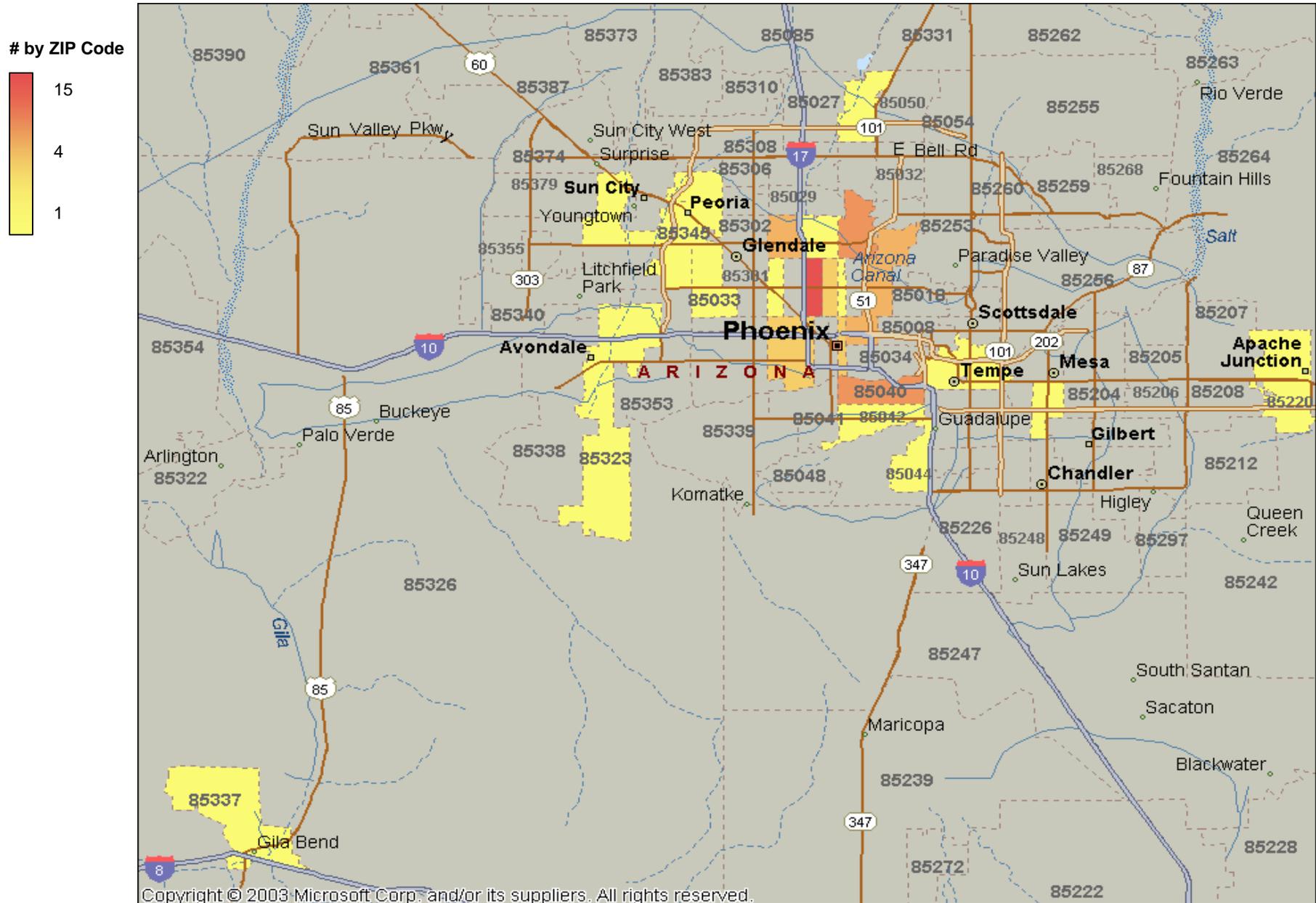
Residence. A map depicting the residence of ‘Aged’ (45 years+) PLWH/A responding to this survey is displayed on the following page at both a 150-mile radius and at a closer view, at a 80-mile radius.

¹ 1) **CD4 – CD4 (T4) or CD4 + CELL COUNT and PERCENT.**

2) **VIRAL LOAD TEST** - Test that measures the quantity of HIV RNA in the blood.

3) **ANTIRETROVIRAL DRUGS** - Substances used to interfere with replication or inhibit the multiplication of retroviruses such as HIV.

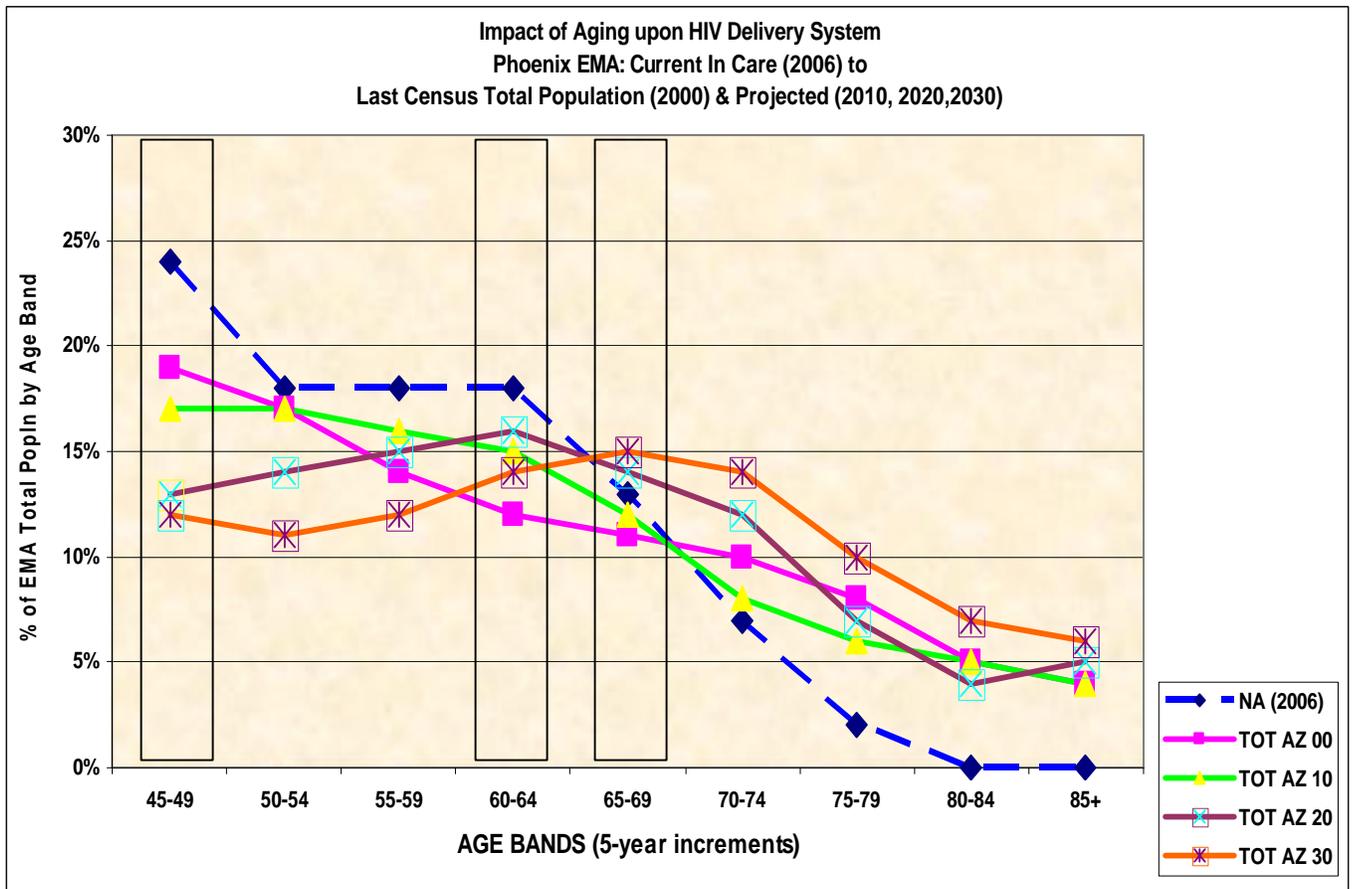
150-mile radius: Residence of 'Aged' (45 years +) In Care respondents to 2006/2007 Needs Assessment



Demographic of General Population compared to PLWH/A 'Aged'. The general population over 45 years of age comprised 34% of the population in the 2000 census, a figure anticipated to increase to 39% by 2010, 45% by 2020 and 52% by 2030. Of these age bands, women exceed men in the general population in the 2-county EMA and continue to increase their representation as they age.

The populations of males and females among the 'aged' in the general population track closely in the 45-49 and 50-54 age bands, with only 3% and 5% more females than males. At the 55 and older age band through the 65-69 age band, women represent 10% more of the population than men. At the 70-74 and 75-79 age bands this gap further increases to 15%, and upon reaching the 80-84 age band, women are 39% more prevalent than men with a doubling of women compared to men at the 85+ age band. This natural gender imbalance is reflected in the aging PLWH/A population, particularly as the disease moves to a chronic condition.

Census projections indicate a rapid and continued escalation in the proportion of 'aged' to the remainder of the population as displayed in the following graph. This graph compares the age bands for the 'aged' PLWH/A in the 2-county EMA to the aging curve at the 2000 census against projections for 2010, 2020 and 2030. As evidence by this graph, the dominant five-year age band is shifting from the 45-49 age group in 2000 (mirrored by the PLWH/A in 2005) to the 60-64 by 2010 and 2020 and 65-69 by 2030.



(Source: U.S. Census Bureau, Projections for Maricopa and Pinal Counties)

**RYAN WHITE IN CARE FRACTION OF PHOENIX EMA PREVALENT HIV/AIDS:
SUBSET OF 'AGED' by Race/Ethnic Group by Gender**

The total In Care, In System population seen at McDowell Health Center is displayed below by age by gender by Race/Ethnic Group . Although males outnumber females (82%:18%), females present an older profile with one-third between 45-54 years of age and over one-quarter between 55-64. Males have a younger profile, with almost three-quarters of the 'aged' between 45-54 years.

TOTAL

Demographic Group/Exposure Category	# over 45 years+ In Care in RW System	45-54	55-64	65-74	75-84	85+
Race/Ethnic		74%	22%	4%	0.4%	0.2%
White, not Hispanic	279	209	63	7	0	0
African-American, not Hispanic	77	56	18	3	0	0
Hispanic	109	75	23	9	1	1
Asian/Pacific Islander	3	3	0	0	0	0
American Indian/ Native American	6	5	1	0	0	0
Multi-race	9	3	3	2	1	0
Unknown/Unreported	21	20	1	0	0	0
TOTAL	504	371	109	21	2	1

Males

Demographic Group/Exposure Category	# over 45 years+ In Care in RW System	45-54	55-64	65-74	75-84	85+
Race/Ethnic		76%	21%	3%	0.2%	0%
White, not Hispanic	242	183	53	6	0	0
African-American, not Hispanic	59	42	15	2	0	0
Hispanic	82	60	16	6	1	0
Asian/Pacific Islander	3	3	0	0	0	0
American Indian/ Native American	5	5	0	0	0	0
Multi-race	5	3	2	0	0	0
Unknown/Unreported	18	17	1	0	0	0
TOTAL	414	313	87	14	1	0

Females

Demographic Group/Exposure Category	# over 45 years+ In Care in RW System	45-54	55-64	65-74	75-84	85+
Race/Ethnic		67%	26%	6%	1%	1%
White, not Hispanic	37	26	10	1	0	0
African-American, not Hispanic	18	14	3	1	0	0
Hispanic	27	15	8	3	0	1
Asian/Pacific Islander	0	0	0	0	0	0
American Indian/ Native American	1	0	1	0	0	0
Multi-race	4	2	1	0	1	0
Unknown/Unreported	3	3	0	0	0	0
TOTAL	90	60	23	5	1	1

PHOENIX EMA, EMERGENT HIV/AIDS AND PREVALENT HIV/AIDS NOTING ‘AGED’

Demographic Group/Exposure Category	AIDS Incidence (01/01/04-12/31/05)		AIDS Prevalence (01/01/05-12/31/05)		HIV Prevalence (01/01/05-12/31/05)	
	#	%	#	%	#	%
Race/Ethnic						
White, not Hispanic	414	50%	2,264	62%	2,532	61%
African-American, not Hispanic	95	11%	417	12%	504	12%
Hispanic	271	33%	814	22%	871	21%
Asian/Pacific Islander	7	1%	33	0.8%	32	1%
American Indian/ Native American	40	5%	121	3%	119	3%
Multi-race	0	0	6	0.2%	76	2%
TOTAL	827	100%	3,655	100%	4,134	100%
Gender						
Male	711	86%	3,232	88%	2,540	86%
Female	116	14%	423	12%	594	14%
TOTAL	827	100%	3,655	100%	4,134	100%
Age						
0-12	1	0.1%	6	0.2%	31	0.8%
13-19	9	1%	12	0.3%	27	0.7%
20-44	585	70.9%	2,048	56%	2,649	64%
45+	232	28%	1,588	43.5%	1,427	34.5%
TOTAL	827	100%	3,655	100%	4,134	100%
Transmission/Exposure						
MSM	510	61.6%	2,297	63%	2,413	58%
IDU	123	14.8%	471	13%	479	12%
MSM/IDU	67	8%	394	11%	288	7%
Heterosexual	112	14%	359	10%	428	10%
Adult/Other	5	0.6%	47	1%	85	2%
Risk not reported	10	1%	87	2%	441	11%
TOTAL	827	100%	3,655	100%	4,134	100%

Source: S. Robert Bailey, Epidemiologist, Office of HIV/AIDS, Arizona Department of Health Services, 2006.

* defined by HRSA as 45 years+

RELATIVE RANKING OF PHOENIX EMA FOR ‘AGED’ (45 years+)

STATISTIC	Phoenix EMA ‘Rank’ (2005)	#1 EMA
AIDS Incidence (new cases)	#32 @ 26%	Santa Rosa, CA @ 60.4%
AIDS Prevalence (living with)	#32 @ 44%	New Haven, CT @ 62%
HIV Prevalence (living with)	#12 @ 35%	Denver, CO @ 66%

Source: Center for Disease Control & Prevention (CDC) HIV/AIDS Reporting System (HARS) database, 2004

Prevalence estimates the current population living with the HIV or AIDS infection.

Incidence or Emergence measures the emerging disease pattern, or those persons newly diagnosed with the disease within the past four years. The emergent diagnosis is the earliest report of HIV infection for each person. Those first diagnosed as HIV would be emergent HIV cases, and those first diagnosed as AIDS would be emergent AIDS. This data is presented in the tables on the following pages for the Phoenix EMA (inclusive of Maricopa and Pinal county HIV/AIDS statistics).

CENTRAL REGIONAL PLANNING GROUP COUNTIES (Maricopa and Pinal Counties)

2004 Population	% of State Population	% State HIV/AIDS Prevalence
3,715,360	64.7	71.9

CURRENT ESTIMATED PREVALENCE:

	Prevalent HIV			Prevalent HIV&AIDS			Cases	% Region Total	Rate Per 100,000
	Cases	% Region Total	Rate Per 100,000	Cases	% Region Total	Rate Per 100,000			
By Gender									
<i>Male</i>	3572	45.4	190.72	3261	41.5	174.12	6833	86.9	364.84
<i>Female</i>	600	7.6	32.57	433	5.5	23.50	1033	13.1	56.07
	4172	53.0	112.29	3694	47.0	99.43	7866	100.0	211.72
By Age									
Under 2	3	0.0	2.42	0	0.0	0.00	3	0.0	2.42
2-12	28	0.4	4.43	6	0.1	0.95	34	0.4	5.38
13-19	27	0.3	7.46	10	0.1	2.76	37	0.5	10.23
20-24	137	1.7	51.33	29	0.4	10.87	166	2.1	62.20
25-29	313	4.0	110.00	132	1.7	46.39	445	5.7	156.39
30-34	481	6.1	163.85	318	4.0	108.33	799	10.2	272.18
35-39	777	9.9	288.27	639	8.1	237.07	1416	18.0	525.34
40-44	952	12.1	347.95	945	12.0	345.39	1897	24.1	693.34
45-49	671	8.5	274.59	711	9.0	290.96	1382	17.6	565.56
50-54	384	4.9	182.67	464	5.9	220.72	848	10.8	403.39
55-59	210	2.7	113.47	243	3.1	131.30	453	5.8	244.77
60-64	94	1.2	63.27	117	1.5	78.75	211	2.7	142.02
65 and Above	81	1.0	19.22	80	1.0	18.98	161	2.0	38.21
Age Unknown	14	0.2	N/A	0	0.0	N/A	14	0.2	N/A
	4172	53.0	112.29	3694	47.0	99.43	7866	100.0	211.72
By Race / Ethnicity									
White Non-Hispanic	2541	32.3	108.73	2278	29.0	97.48	4819	61.3	206.22
Black Non-Hispanic	505	6.4	337.70	428	5.4	286.21	933	11.9	623.91
Hispanic	894	11.4	84.65	823	10.5	77.92	1717	21.8	162.57
*A/PI/H Non-Hispanic	34	0.4	34.62	33	0.4	33.60	67	0.9	68.23
**AI/AN Non-Hispanic	123	1.6	164.88	124	1.6	166.22	247	3.1	331.11
***MR/O Non-Hispanic	75	1.0	N/A	8	0.1	N/A	83	1.1	N/A
	4172	53.0	112.29	3694	47.0	99.43	7866	100.0	211.72
By Mode of Transmission									
+MSM	2444	31.1	N/A	2320	29.5	N/A	4764	60.6	N/A
++IDU	481	6.1	N/A	480	6.1	N/A	961	12.2	N/A
MSM / IDU	289	3.7	N/A	391	5.0	N/A	680	8.6	N/A
Heterosexual	437	5.6	N/A	367	4.7	N/A	804	10.2	N/A
+++O/H/TF/TPR	83	1.1	N/A	47	0.6	N/A	130	1.7	N/A
++++NRR/UR	438	5.6	N/A	89	1.1	N/A	527	6.7	N/A
	4172	53.0	112.29	3694	47.0	99.43	7866	100.0	211.72

* Asian Pacific/Islander/Hawaiian
 ** American Indian/Alaskan Native
 *** Multiple Race/Other Race

+ Men having Sex with Men
 ++ Injection Drug Use
 +++ Other/Hemophilia/Transfusion and Blood Products/Transplant Recipient
 ++++ No Reported Risk/Unknown Risk

Maricopa and Pinal Counties

REGIONAL INCIDENCE 2000-2004:

	Emergent HIV			Emergent AIDS			Emergent HIV/AIDS		
	Cases	% Region Total	Rate Per 100,000	Cases	% Region Total	Rate Per 100,000	Cases	% Region Total	Rate Per 100,000
By Gender									
Male	1515	55.1	17.23	857	31.1	9.75	2372	86.2	26.97
Female	258	9.4	2.97	122	4.4	1.40	380	13.8	4.38
	1773	64.4	10.14	979	35.6	5.60	2752	100.0	15.75
By Age									
Under 2	6	0.2	1.03	3	0.1	0.52	9	0.3	1.55
2-12	11	0.4	0.37	1	0.0	0.03	12	0.4	0.40
13-19	41	1.5	2.41	7	0.3	0.41	48	1.7	2.83
20-24	207	7.5	16.41	44	1.6	3.49	251	9.1	19.89
25-29	305	11.1	22.68	102	3.7	7.59	407	14.8	30.27
30-34	349	12.7	25.34	180	6.5	13.07	529	19.2	38.41
35-39	333	12.1	25.33	213	7.7	16.20	546	19.8	41.52
40-44	246	8.9	19.08	180	6.5	13.96	426	15.5	33.04
45-49	139	5.1	12.35	105	3.8	9.33	244	8.9	21.67
50-54	68	2.5	6.89	77	2.8	7.80	145	5.3	14.69
55-59	31	1.1	3.79	39	1.4	4.77	70	2.5	8.56
60-64	26	0.9	3.96	10	0.4	1.52	36	1.3	5.49
65 and Above	11	0.4	0.54	18	0.7	0.89	29	1.1	1.43
Age Unknown	0	0.0	N/A	0	0.0	N/A	0	0.0	N/A
	1773	64.4	10.14	979	35.6	5.60	2752	100.0	15.75
By Race									
White Non-Hispanic	974	35.4	8.65	500	18.2	4.44	1474	53.6	13.09
Black Non-Hispanic	247	9.0	36.42	117	4.3	17.25	364	13.2	53.67
Hispanic	472	17.2	9.95	315	11.4	6.64	787	28.6	16.59
*A/PI/H Non-Hispanic	19	0.7	4.31	8	0.3	1.82	27	1.0	6.13
**AI/AN Non-Hispanic	56	2.0	15.77	38	1.4	10.70	94	3.4	26.47
***MR/O Non-Hispanic	5	0.2	N/A	1	0.0	N/A	6	0.2	N/A
	1773	64.4	10.14	979	35.6	5.60	2752	100.0	15.75
By Risk Factor									
+MSM	1085	39.4	N/A	612	22.2	N/A	1697	61.7	N/A
++IDU	237	8.6	N/A	143	5.2	N/A	380	13.8	N/A
	143	5.2	N/A	75	2.7	N/A	218	7.9	N/A
Heterosexual	226	8.2	N/A	131	4.8	N/A	357	13.0	N/A
+++O/H/TF/TPR	26	0.9	N/A	11	0.4	N/A	37	1.3	N/A
++++NRR/UR	56	2.0	N/A	7	0.3	N/A	63	2.3	N/A
	1773	64.4	10.14	979	35.6	5.60	2752	100.0	15.75

* Asian Pacific/Islander/Hawaiian
 ** American Indian/Alaskan Native
 *** Multiple Race/Other Race

+ Men having Sex with Men
 ++ Injection Drug Use
 +++ Other/Hemophilia/Transfusion and Blood Products/Transplant Recipient
 ++++ No Reported Risk/Unknown Risk

Project Design

The objectives of this needs assessment study included the following:

- 1) To identify the extent and types of service needs among In Care ‘Aged’ (45 years+) PLWH/A in Maricopa and Pinal Counties; and
- 2) To identify the service Gaps and Barriers to care as perceived by ‘Aged’ (45 years+) PLWHA in Maricopa and Pinal counties.
- 3) To determine unique features of the In Care ‘Aged’ (45 years+) subgroup that provide insight into means to facilitate care entry and maintain them in primary medical care.

The sample for surveying the ‘In Care’ population was first determined by establishing a goal of 10% participation from the total number of ‘Aged’ (45 years+) PLWHA receiving Ryan White funded primary care services at McDowell Health Care Center. Clinic data indicates that 504 ‘Aged’ (45 years+) PLWHA received primary care services in the 2006 project year. Therefore, the 10% target for ‘In Care’ Survey Respondents was set at 50 persons. A target sample set by demographic and risk profile was used to establish an accurate means of matching survey participants to this dataset in order to reflect the total ‘In Care’ population. Included below is the Target Sample Set for the ‘Aged’ (45 years+) needs assessment study.

Target Sample Set

Phoenix EMA 2006-In Care RW Target Sample Set*	<i>In Care Data</i>	<i>Target</i>	<i>Actual</i>	<i>+/-</i>
<i>Race/Ethnicity</i>				
‘Aged’ (45 years+)	504	50	56	6
<i>Gender</i>				
Male	414	41	40	(1)
Female	90	9	16	7
Transgender				
Total	504	50	56	6
<i>Exposure Category</i>				
MSM	61%	31	30	(1)
Injection drug use (IDU)	12%	6	6	0
IDU/MSM	9%	4	9	5
High Risk Heterosexual	10%	5	10	5
Other (transfusion)	2%	1	-	(1)
Unknown	6%	3	1	(2)
Total	100%	50	56	6

The ‘In Care’ survey process was implemented under the direction of Collaborative Research. The survey site for the survey process included the Ryan White funded McDowell Health Care Center. This service provider was selected to access those ‘Aged’ (45 years+) PLWHA currently receiving RW funded services and to *ensure a minimum of duplication* among survey participants. Survey Respondents received a \$20 Safeway food card for participating in the survey process.

Chapter 2: ‘Aged’ (45 years+) Literature Search

A literature search was conducted prior to conduct of the ‘Aged’ (45 years+) Needs Assessment to comprehensively assess the state of the field, determine possible hypotheses related to service needs, use, barriers and gaps for this severe need group, and to further describe the challenges facing this important and rapidly growing subset within the Phoenix EMA.

Five (5) major categories of literature findings are excerpted below that consolidate findings from the comprehensive bibliography appended as **Appendix A**.

1. Self Management:

- 1) Observed tendency in several EMAs long-term surviving Anglo MSM to ‘self manage’ their HIV care
 - a. Periodic lab testing of blood levels
 - i. CD-4
 - ii. Viral load
 - b. Majority are not taking antiretroviral therapy (ART), few are on ART
- 2) Study focus in Out of Care is to determine success in self care
 - a. Estimate number and percent of Phoenix EMA self-managing care and confirm that Anglo MSM are single largest subgroup of self-managers.
 - b. Determine reasons why a subset of Anglo MSM prefer to self-manage their disease
 - c. Assess issues with self-care (problems accessing lab values, knowledge of most recent advances in antiretroviral therapy, services needed to support self-management)
- 3) Present alternative of persuading this group to enter modified care system:
 - a. Use Chronic Care Model² used by individuals with other chronic diseases (diabetes, uninsured with hyperlipidemia, hypertension)
 - b. Formulate model for PLWH/A with minimal organized system involvement but authorized clinical intervention to formally monitor lab values and drug levels
 - c. Incorporate five (5) elements of patient self-care:
 - i. Community resource availability
 - ii. Health care organization linkage for assistance in self-monitoring
 - iii. Decision support protocols to guide PLWH/A and clinician
 - iv. Delivery system design in form of physician feedback, possibly structured through group medical appointments
 - v. Self-management support through assistance (even if on-line) with goal-setting and problem-solving.

Ryan White Titles reporting tendency to ‘self-manage’ HIV:

RYAN WHITE TITLE I	RYAN WHITE TITLE II
<ul style="list-style-type: none"> • Portland, Oregon 	<ul style="list-style-type: none"> • Maine
<ul style="list-style-type: none"> • Denver, Colorado 	
<ul style="list-style-type: none"> • New Haven, Connecticut 	
<ul style="list-style-type: none"> • Sacramento, California 	

² Presented by HRSA in August 2005 Special Projects of Significance (SPNS)

2. Comorbidities/HIV & Chronic Illness

Nationally, little research exists about 'Aged' PLWH/A and prevalence of comorbidities other than HIV/AIDS. Two-three EMAs have conducted age-specific needs assessments, and of these, they report anywhere from 4-6 comorbid conditions compared to 2-3 in the below 45 years of age population. This compares to 3.8 in the Phoenix EMA over 45 respondent pool. The most common comorbid conditions reported by Phoenix EMA over 45 respondents to this survey that reflect prior studies were: a) diabetes b) cardiac c) cancer and d) mental health.

3. Epidemiology

'Aged' PLWH/A nationally constitute approximately 15% of the overall infected community. This compares to a figure of 44% of PLWA and 35% of PLWH for 2005. New AIDS cases continue to increase with a 2005 figure of 32%.

The Phoenix figure is higher than the remainder of the nation, with a ranking in 2005 of #12 for PLWH that are 'aged', #32 for PLWA and #32 for new AIDS cases (out of 51). This ranking dramatically increased from 2004 for PLWH, and slightly increased (2 slots) for PLWA and new AIDS cases.

The 'Aged' group continues to rapidly escalate as the general population ages and incidence among those over 45 years of age rises compared to the general population. Both age bands (under 20 years of age and over 45) show more rapid incidence than the large mid-age band of 21-44. The aged differ from the 'young' and mid-age bands in a higher percentage (52%) of AIDS diagnoses versus HIV, MSM constituting the largest group and high-risk heterosexual women rising at the highest rate for the newly diagnosed over 60 years of age.

4. Disease progression

Due to the confounding symptoms of HIV and aging and lack of awareness by general physicians about the risk of HIV due to risky sexual practice and/or drug use among those over 45 years of age, delayed diagnosis upon symptom onset is common among the 'aged'.

The few studies conducted by other EMAs show that twelve-eighteen months transpired on average from symptom onset and attempts to determine condition to an HIV diagnosis. Often the diagnosis was stumbled upon through blood testing for other diseases or was instigated by the individual, not their physician. The Phoenix EMA 'Aged' respondents to this Needs Assessment reported an average delay from symptom presentation to accurate diagnosis of eighteen months. This was longer for high-risk heterosexual women compared to MSM.

Disease progression for the women responding to the Needs Assessment was typical of those found in other studies. Due to menopause and lack of need for condom use, risk was higher, aging caused the vaginal walls to thin and lose lubrication increasing the probability of acquiring the virus and progressing the disease.

5. Social Isolation

The profound sense of social isolation reported in other studies was echoed by respondents to the Phoenix 'Aged' Needs Assessment. Few groups exist to deal with this specific subpopulation, with senior groups hostile to admission of HIV/AIDS, at a time support is sorely needed. Few age-specific clinical trials, research programs or education/prevention groups exist for this subgroup. AIDS Network of Arizona is an exception to this rule. This group sponsors support groups and information specifically tailored to the needs of PLWH/A over 50 years of age.

Chapter 3: ‘Aged’ (45 years+) In Care Survey Findings³

The 2006 HIV/AIDS Needs Assessment provides a “snapshot” of the ‘Aged’ (45 years+) PLWHA community service needs, usage, barriers, and gaps as expressed by consumers of HIV related services. The goal of the ‘In Care’ survey process was to achieve a 10% participation rate by the ‘In Care/In System’ clients, hereafter referred to as ‘In Care’ population (N=56). The actual ‘In Care’ participation rate was almost 11% (N=56). This level of participation represents a baseline for future assessments of need among ‘Aged’ (45 years+) PLWHA in the EMA.

Overview of In Care Survey Results

The ‘In Care’ client surveys were scheduled over a two-month period in the Winter of 2006/early 2007, with 56 total surveys completed. The tables below indicate the gender, sexual orientation, and age of the responding ‘Aged’ (45 years+) ‘In Care’ survey population.

Demographic Profile of ‘Aged’ (45 years+) In Care Survey Participants

Gender

		#	%
GENDER	Male	40	71%
	Female	16	29%
Total		56	100%

Sexual Orientation

		#	%
Sexual	Gay	30	54%
Orientation	Bisexual	6	11%
	Straight	20	35%
Total		40	100%

Age

Over half of the ‘Aged’ (45 years+) survey participants (60%) report ages in the 45-59 age range. Another 18% are between 60-64 years of age, with only 22% above the age of 65, the age typically associated in the general population with ‘aged’. No respondents were 80 and above, a figure expected to change with advancing age of the general population.

To confirm one of our initial hypotheses, 25% of ‘Aged’ respondents were long-term survivors (diagnosed in 1992 or before) with a slightly higher figure for those initially diagnosed with AIDS (31%). The majority (75%) of respondents had been diagnosed after 1992, with 69% of initial AIDS diagnoses consisting of newer infected individuals.

³ In Care – defined by HRSA as receiving one or more of the following services 1) Viral Load test 2) CD4 Cell Count and/or 3) Antiretroviral drugs within the past 12 months

Age Groups

Age Range	#	%
45-49	13	24%
50-54	10	18%
55-59	10	18%
60-64	10	18%
65-69	7	13%
70-74	4	7%
75-79	1	2%
TOTAL	55	100%

Race/ Ethnic background

Group	#	%
Caucasian	28	50%
African American	12	21%
Hispanic/Latino	11	20%
American Indian	4	7%
Asian/Pacific Islander	1	2%
Total	56	100%

The majority of respondents are Caucasian (50%), followed by African American (21%), Hispanic/Latino (20%), Native American (7%) and 1 Asian (2%). No multi-racial PLWH/A responded to this survey.

Zip Code of Residence

The residence of 'Aged' respondents are scattered throughout the 2-county EMA in patterns reflective of the general population. The only zip code with high report was 85015, with 25% of total respondents reporting this residence. (see maps)

ZIP	#	%
85004	2	3.6%
85006	3	5.4%
85009	2	3.6%
85012	1	1.8%
85013	2	3.6%
85015	14	25.0%
85016	3	5.4%
85019	1	1.8%
85020	5	8.9%
85021	1	1.8%
85024	1	1.8%
85033	1	1.8%
85040	5	8.9%
85042	1	1.8%
85044	1	1.8%
85051	3	5.4%
85210	1	1.8%
85220	1	1.8%
85303	1	1.8%
85305	1	1.8%
85315	1	1.8%
85323	1	1.8%
85337	1	1.8%
85345	1	1.8%
85381	1	1.8%
85851	1	1.8%
TOTAL	56	100.0%

Location of HIV Diagnosis

Almost half of the survey respondents (48%) learned their HIV status in Arizona, while 52% report the location of diagnosis in other states, including New Mexico, Texas, California and Nevada. This figure is much higher than that of other severe need groups, which range from 55-65%, indicating the immigration of the ‘aged’ subgroup and the higher proportion of long-term survivors.

CITY	STATE	#	%
PHOENIX	AZ	26	46%
LOS ANGELES	CA	5	9%
SAN FRANCISCO	CA	5	9%
CHICAGO	IL	3	5%
DENVER	CO	2	4%
ALBUQUERQUE	NM	1	2%
BRONX	NY	1	2%
BROOKLYN	NY	1	2%
DALLAS	TX	1	2%
LAS VEGAS	NV	1	2%
MEMPHIS	TN	1	2%
MEXICO		1	2%
NO ANSWER		1	2%
OAKLAND	CA	1	2%
PAYSON	AZ	1	2%
PHILADELPHIA	PA	1	2%
SAN DIEGO	CA	1	2%
ST. PETERSBURG	CA	1	2%
TAMPA	FL	1	2%
WICHITA FALLS	TX	1	2%
Grand Total		56	100%

HIV Transmission Risk

Over half of the ‘Aged’ (45 years+) In Care respondents (54%) report acquiring HIV as a result of MSM risk behavior; 14% as a result of heterosexual behavior; 11% of all respondents cite injection drug use as the mode of HIV infection. Over 10% report their mode of HIV transmission as “unknown”.)

MEDIUM OF HIV INFECTION	#	%
Male sex with male	30	54%
Heterosexual sex	10	18%
Injection Drug Use	10	18%
Sex with Drug User	6	11%
TOTAL	56	100%

HIV Status

HIV STATUS	#	%
HIV	37	65%
AIDS	19	35%
HIV to AIDS (seroconverted) within 1 year of diagnosis	6	11%
TOTAL	56	100%

Although the proportion of those initially diagnosed with HIV reported by survey respondents (65%) is consistent with that of the overall EMA epidemiology (68% HIV), 14% of respondents reported seroconversion to AIDS within one year of their initial HIV diagnosis. This figure results in three-quarter of the survey respondents carrying an AIDS burden (76%). This rapid seroconversion qualifies the ‘aged’ group as meeting the CDC technical definition of ‘late to care’ (defined as either an initial AIDS diagnosis or seroconversion to AIDS within one year or less following an initial HIV diagnosis).

Income Level

The majority of the ‘Aged’ (45 years+) In Care respondents (N=34 or 61%) report incomes at or below the federal poverty level, in the \$0-9,999 range. Nine respondents report their current income as ranging between \$10-19,000; two respondents report an income between \$20-29,000. A high percentage (20%) or eleven individuals would not disclose their annual income.

ANNUAL INCOME	#	%
0-9,999	34	61%
10,000-19,999	9	16%
20,000-29,999	2	4%
30,000-39,999	0	0%
40,000-49,999	0	0%
Over 50,000	0	0%
Did not disclose	11	20%
TOTAL	56	100%

Ever Homeless Only 7% of the total ‘Aged’ survey respondents report a current period of homeless, with 10% stating that they had prior homeless episodes. This finding indicates relative housing stability despite ranking of housing as the 2nd highest barrier to facilitate entry into and retention in HIV primary care services.

Employment

Less than half of the ‘Aged’ (45 years+) In Care survey respondents (38%) report current employment, while almost two-thirds or 62% are currently unemployed.

EMPLOYED		UNEMPLOYED	
#	%	#	%
21	38%	35	62%
56	100%		

Living Arrangements

Only 10% of the ‘Aged’ (45 years+) respondents report owning their home; over one-half (55%) report currently renting a home or apartment; and almost one-third (30%) of all survey participants report being ‘temporarily housed’, currently staying with friends or relatives. Two ‘Aged’ (45 years+) PLWHA report current homelessness, usually staying in a shelter.

Only 25% of the total survey group reports currently receiving any form of rental assistance.

RESIDENCE	#	%
Own your home	3	5%
Rent	40	71%
Live with a Friend/Relative	10	18%
Live in a halfway house	1	2%
Other	2	4%
Total	56	100%

Ever Homeless

Only 7% of the total ‘Aged’ survey respondents report a current period of homeless, with 10% stating that they had prior homeless episodes. This finding indicates relative housing stability despite ranking of housing as the 2nd highest barrier to facilitate entry into and retention in HIV primary care services.

EVER HOMELESS RESPONSE	#	%
Never	46	82%
Currently	1	2%
In past 2 years, but not now	1	2%
Longer than past 2 years, but not now	7	12%
Prefer not to answer	1	2%
Total	56	100%

Education Level

The ‘Aged’ (45 years+) In Care respondents report a low level of education with only 25% possessing some college or a college level degree, and 14% reporting graduation from high school. Over a third (36%) of the ‘Aged’ (45 years+) In Care survey participant group reports only some high school or grade school education or less. ***These education levels are consistent with the majority of income reported, although a caveat exists for the high (20%) of ‘would not disclose’ respondents to the income question.***

EDUCATION	#	%
Grade school or less	10	18%
Some high school	10	18%
High school grad/GED	8	14%
Technical or Trade School	14	25%
Some College	11	20%
College degree	3	5%
Graduate level	0	
Other:	0	
Total	56	100%

Incarceration in Past Year

Five ‘Aged’ (45 years+) survey participants (or 9% of the total respondent pool) report having been incarcerated (in jail or prison) during the past year. Another 5 or 9% refused to respond to this question indicating a higher incarceration rate than 9% among the ‘aged’.

YES	%	NO	%	WOUD NOT DISCLOSE	%
5	9%	46	82%	5	9%
56	100%				

Health Insurance

HEALTH INSURANCE		
	#	%
Private	1	2%
Medicare	10	17%
Medicaid (AHCCCS)	40	67%
VA	7	12%
None	1	2%
Delta Dental	0	0%
Other	1	2%
TOTAL	60	100%

Six individuals (11%) are “dual eligible” (insured by both Medicare and Medicaid). The majority of ‘Aged’ are covered through Medicaid (AHCCCS), with 17% covered by Medicare. This low Medicare coverage reflects the age categories, with the dominance of respondents (78%) in the 45-49, 50-54, 55-59 and 60-64 age bands. The 12% of Veterans Administration is interesting given conduct of the surveys at McDowell Health Care Center.

Primary Care Visit and Lab Monitoring Indicators of In Care Status

All 100% of the ‘Aged’ (45 years+) PLWHA report excellent In Care active status, with all persons reporting seeing their physician and receiving laboratory services in the past six months. The vast majority (82%) report primary care and lab services during the last quarter of 2006.

'IN CARE' COMPLIANCE	DOCTOR		CD4		VIRAL LOAD	
	#	%	#	%	#	%
Frequency of Visit						
Every month	23	41%	12	21%	12	21%
Every Two months	9	16%	18	32%	17	30%
Every Three months	14	25%	18	32%	18	32%
Every Four months	4	7%	3	5%	3	5%
> 4 months, less than 6	6	11%	5	9%	6	11%
Total	56	100%	56	100%	56	100%

Current Antiretroviral Therapy

The majority of 'Aged' (45 years+) survey respondents (84%) report receipt of antiretroviral therapy, as evidenced in the table below.

ART			
Yes		No	
#	%	#	%
47	84%	9	16%
56	100%		

As evidenced by the following tables, the 'Aged' (45 years+) survey respondents reported substantially significant levels of mental health and substance abuse disorders (39% AND 32%, respectively). ***Fifty-seven percent of the survey participants reported a history of STDs and 79% reported a history of other disease processes in addition to HIV disease.***

History of Mental Illness-Diagnosis and/or Treatment

YES		NO	
#	%	#	%
22	39%	34	61%
56	100%		

History of Substance Abuse-Diagnosis and/or Treatment

YES		NO	
#	%	#	%
24	43%	32	57%
56	100%		

History of Diagnosis and/or Treatment of STDs

YES		NO		PREFER NOT TO ANSWER	
#	%	#	%	#	%
32	55%	23	45%	1	3%
56	100%				

History of Diagnosis and/or Treatment of Diseases other than HIV Disease

YES		NO	
#	%	#	%
42	79%	14	21%
56	100%		

Comorbidities

DISEASE	#	%
Cardiac/Heart	9	21%
High Blood Pressure	7	17%
Cancer	7	17%
Diabetes or metabolic problem	6	14%
Hepatitis C	6	14%
Nerve	1	2%
Tuberculosis	1	2%
Other	5	12%
Total	42	100%

The highest reported comorbid current conditions are (1) Cardiac at 21% (2) Hypertension at 17% and Cancer at 17% (3) Diabetes/metabolic at 14% and Hepatitis C at 14%

The most common opportunistic infection reported was oral thrush (17% or 7). Of ‘aged’ respondents reporting opportunistic infections, 47% experienced these prior to their HIV diagnosis and 53% after their diagnosis. This equivalent fraction matches the ‘late to care’ seroconversion pattern.

Over twenty percent (23%) perceived that their diseases other than HIV worsened following their diagnosis, with this one-fifth correlating this deterioration to their HIV medications.

Eleven percent or 6 individuals (38% of the responding women) reported ‘ever’ taking hormone replacement therapy, with only 1 currently taking HRT, and 5 with a history of HRT use.

Dental Care

Extensive questions were posed about Oral Health due to the tendency of ‘aged’ individuals to experience worsening oral health with age. Oral health is a crucial determinant of HIV disease progression, and also an indicator of overall health due to its role as a sign of inflammation. In addition, this service category consistently ranks as the #1 gap (need service, can’t get).

SEEN	DENTIST	PAST	YEAR?
Yes	%	No	%
31	55%	25	45%
56	100%		

TEETH	EXTRACTED	PAST	YEAR?
Yes	%	No	%
22	39%	34	61%
56	100%		

# TEETH EXTRACTED	#	%
1	7	32%
2-4	14	64%
5-7	0	
8+	1	5%
Total	22	100%

THRUSH	IN	PAST	YEAR?		
Yes	%	No	%	Don't Know	%
1	2%	46	82%	9	16%
56	100%				

EVER	HAD	DRY	MOUTH?
Yes	%	No	%
13	23%	43	77%
56	100%		

Frequency IF Ever Dry Mouth	#	%
Daily		
Weekly	6	27%
Always	6	27%
Other	1	5%
Total	13	59%

EVER	SWELLING	FACE/NECK?	
Yes	%	No	%
9	16%	47	84%
56	100%		

When Experienced

HIV DIAGNOSIS	#	%
Before	6	67%
After	3	33%
Total	9	100%

EVER	SORES	IN	MOUTH?
Yes	%	No	%
13	23%	43	77%
56	100%		

When Experienced

HIV DIAGNOSIS	#	%
Before	9	69%
After	4	31%
Total	13	100%

A Use, Needs, Gaps and Barriers ranking was developed for all 'Aged' (45 years+) 'In Care' respondents. The 2006/2007 'Aged' (45 years+) HIV/AIDS Needs Assessment provides a "snapshot" of the community service needs, barriers, and gaps as expressed by AI/NA consumers of HIV related services. The rankings of the Needs Assessment were displayed for all 'In Care' respondents, with separation into Need, Use, Gap and Barrier. This can be further defined as:

Need	Number of 'In Care' client survey respondents who stated "I currently need this service."
Use	Number of 'In Care' client survey respondents who indicated service use in the past year
Gap	Sum of 'In Care' client survey respondents who answered 'Yes' to Need and 'No' to availability of that service
Barrier	Number of 'In Care' client survey respondents who indicated that a service is 'Hard to Get'

NEED

The highest priority HIV service needs reported by the 'Aged' (45 years+) In Care survey participants, in rank order, include: 1) HIV Medications; 2) Other Medications; 3) Primary Medical Care; 4) Employment; 5) Housing; 6) Dental Care; 7) Financial Assistance tied with Case Management; 8) Specialty Medical Care; 9) Home Health Care tied with Hospice and 10) Transportation..

The Top Ranked NEEDS for ALL 'Aged' (45 years+) In Care respondents were:

Service Category Description	Need Rank
HIV Medications	1
Other Medications	2
Primary Medical Care	3
Employment/Job Counseling	4
Housing	5
Dental Care	6
Financial Assistance and Case Management	7
Specialty Medical Care	8
Home Health/Hospice	9
Transportation	10

Service USE

As evidenced in the Need/Use table below, the services reported as most often 'used' by 'Aged' (45 years+) PLWHA are similar though distinct from those most 'needed'.

The Top Ranked Service USE for ALL 'Aged' (45 years+) In Care respondents was:

Service Category Description	Use Rank	Need Rank
Primary Medical Care	1	3
HIV Medications	2	1
Other Medications	3	2
Transportation	4	10
Mental Health Counseling	5	NR
Employment	6	4
Financial Assistance	7	7
Case Management	8	7
Dental/Oral Health	8	6
Housing	9	5

Top Ranked Service GAPS for ALL ‘Aged’ (45 years+) In Care respondents were:

Service Category Description	Gap Rank	Need Rank
Dental	1	6
Financial Assistance	2	7
Employment/Job Counseling	3	4
Housing	4	5
Transportation	5	10

The ‘Aged’ (45 years+) In Care survey respondents ranked the following services as “unavailable”:

1. Dental services
2. Financial assistance
3. Employment/ Job Counseling (specific to older group)
4. Affordable housing
5. Transportation

GAP REASONS

The major reasons offered by ‘Aged’ (45 years+) In Care survey respondents to explain the unavailability of the perceived service Gaps were funding-related (“not enough funds”, or “Don’t know where to apply”). (See table below)

Reasons Cited for Service GAPS for ALL ‘Aged’ (45 years+) In Care respondents:

Service Category Description	Gap Rank	Gap Reasons
DENTAL	1	Need dentures, need implants, no funds for restoration, Can only get teeth extracted
FINANCIAL ASSISTANCE	2	Limited to few times a year –problem when I have a really bad year after not requesting assistance at all.
EMPLOYMENT/ JOB COUNSELING	3	Insufficient resources for people my age—aimed at younger demographic
HOUSING	4	Lack of affordable housing, Long wait lists for Section 8 or ShelterPlus Care
TRANSPORTATION	5	Not enough funds, form of vouchers doesn’t work for me

Service BARRIERS

The top ranking services perceived as “hardest to get” by ‘Aged’ (45 years+) PLWHA include, in rank order: 1) Transportation; 2) Housing; 3) Specialty Medical Care; 4) Other Medications; and 5) Employment/ Job Counseling.

The Top Ranked Service BARRIERS for ALL ‘Aged’ (45 years+) In Care respondents were:

Service Category Description	Barrier Rank	Need Rank
Transportation	1	10
Housing	2	5
Specialty Medical Care	3	8
Other Medications	4	2
Employment/ Job Counseling	5	4

Reasons for BARRIERS

‘Aged’ (45 years+) In Care survey respondents primarily cited funding-related reasons to explain the difficulty in accessing most of the services ranked as service barriers. Clinic hours and work schedule difficulties account for the difficulty in accessing Primary Medical Care.

Reasons Cited for Service BARRIERS for ALL ‘Aged’ (45 years+) In Care respondents:

Service Category Description	Barrier Rank	Need Rank	Barrier Reasons
Transportation	1	10	Not enough funds, form of vouchers doesn’t work for me
Housing	2	5	Lack of affordable housing, Long wait lists for Section 8 or ShelterPlus Care
Specialty Medical Care	3	8	Need more specialists that focus on PLWH/A that are older, especially OB/GYN (8/16 women respondents)
Other Medications	4	2	Need to help afford other medications for comorbid conditions other than HIV
Employment/ Job Counseling	5	4	Despite apparent resources, no interest in helping older people.

Chapter 4: Recommendations for Comprehensive Strategic Plan

1) Work with primary care physicians and larger healthcare community to educate them about need to test for HIV in older population.

2) Address Service GAPS inclusive of:

- Dental
- Financial Assistance
- Legal aid
- Housing
- Transportation

3) Address Service BARRIERS including:

- Transportation
- Housing
- Specialty Medical Care
- Other Medications
- Employment/ Job Counseling

4) Develop self-managed module for HIV Case Management.

5) Consider convening Focus Groups, surveys or other appropriate means to further explore the underlying reasons for the perceived barriers in Specialty Medical Care and Other Medications.

Specifically focus on availability of OB/GYN specialists for older women with HIV.

6) Continue to pursue avenues to secure funding for ‘higher’ end dental services such as dentures, implants.

Chapter 5: Self-Management Module

Applying Elements of the Chronic Care Model to HIV/AIDS Clinical Care: Moving CARE Act clients from intensive case management toward self-management

Health Resources and Services Administration
HIV/AIDS Bureau – Special Projects of National Significance
August 2005

Objectives

The purpose of the present literature review was (1) to examine the Chronic Care Model (CCM) as applied to the management of various chronic illnesses, (2) to evaluate the effectiveness of interventions implementing components of the CCM on patient outcomes, and (3) to identify which components of the CCM can be readily integrated into current Ryan White Care Act initiatives and policy applications as they relate to enhancing the quality of care for persons living with HIV/AIDS (PLWHA).

Background

The development of highly active antiretroviral therapy (HAART) has led to a significantly lengthened survival period in millions of people living with HIV. As a result, AIDS is now widely accepted as a chronic illness (Siegel and Lekas, 2002), and as such requires ongoing primary care management (Bartlett, Cheever, Johnson & Paauw, 2004). While treatment advances are keeping more people with HIV alive for longer, it presents new challenges for how to best provide effective long-term care and management given that our current health delivery systems are designed to respond to acute illnesses (Wagner, Austin & Von Korff, 1996; WHO, 2005).

Chronic illnesses are usually incurable. Consequently, medical care efforts are directed at containing a disease, slowing its progression, and managing symptoms related to it. Most chronic illnesses require adherence to some type of treatment regimen, and typically involve self-care (self-monitoring of symptoms) on the part of the patient. In addition, chronic illnesses also bear some stigma. The degree to which this plays a role in disease management largely depends on the particular condition and on associated factors, such as whether the person is perceived as being responsible for acquiring the disease or whether the disease is communicable.

Today, HIV/AIDS is defined, from both a clinical and policy perspective, as a chronic health condition (Clarke, 1994). However, several features of HIV/AIDS make the management of such a condition profoundly different from other chronic illnesses, such as diabetes, asthma, and arthritis. First, adherence to antiretroviral regimens is complex and often poor due to their rigid dosing schedules, dietary guidelines, and side effects. This problem is extremely concerning given that intermittent non-adherence to HIV therapy can lead to drug resistant strains of the virus (Smith, Rublein, Marcus, Brock, and Chesney, 2003). Second, daily self-monitoring takes on a distinct approach with HIV/AIDS compared to a chronic condition like diabetes. Someone with diabetes can monitor their blood sugar levels throughout the day and can use that information to alter their health-related behaviors if necessary. This is not the case with people living with HIV/AIDS. There is no test that they can self-administer that can provide them with immediate feedback they can use to make adjustments to the way they manage their illness. Lastly, HIV/AIDS stigma persists and discrimination and social ostracism experienced by many infected individuals is unlike the negative attitudes faced by persons with other chronic conditions. In 1999, almost 50% of people polled felt those with AIDS were responsible for contracting the disease. A substantial proportion of those same people polled also had several misconceptions regarding transmission of HIV/AIDS which are likely associated with the enduring stigma attached to the illness (Siegel and Lekas, 2002).

The aforementioned factors which distinguish HIV/AIDS from other chronic illnesses are important to consider when adapting models of care, such as the Chronic Care Model (CCM) to improving the health and quality of life of PLWHA.

Overview of the Chronic Care Model

Recognizing that the majority of chronic illness care is handled within a primary care setting and that health providers spend a significant amount of time treating patients with chronic illness, the Chronic Care Model (CCM) was developed as a guide to implementing effective chronic care. The CCM represents a major shift of chronic care delivery from a reactive acute illness approach to a system in which informed, proactive patients interact with prepared health care teams (Bodenheimer, Wagner & Grumbach, 2002a). Figure 1 illustrates this interaction along with the following six elements that make up the CCM:

1. **Community resources** refer to linkages between provider organizations and community-based resources, e.g., self-help groups, senior centers
2. **Health care organization** includes the goals and policies of the provider organization.
3. **Decision support** refers to making available evidence-based knowledge through clinical practice guidelines and physician education.
4. **Delivery system design** may involve altering the structure of medical practice, creating collaborative practice teams, implementing planned visits, and case-management of high-risk patients.
5. **Clinical information systems** are reminder systems that help health care providers comply with practice guidelines, feedback to physicians showing their performance on chronic illness measures (HbA1c and lipid levels), registries for planning individual patient care.
6. **Self-management support** involves patient education and training in skills such as goal-setting and problem-solving.

Results

Has implementation of the CCM led to improvements in chronic care? In an attempt to answer this question, we searched PubMed (MEDLINE) for studies which have implemented and evaluated the complete CCM. Our findings were limited to the one study summarized in Table 1.

Table 1. Implementation and Evaluation of the Complete Chronic Care Model															
Study	Adapting the Chronic Care Model to Treat Chronic Illness at a Free Medical Clinic (Stroebe et al., 2004)														
Methods	Prospective cohort study														
Participants	Uninsured, highly transient patient population living or working in the Rochester, Minnesota area and receiving care at a free clinic 149 enrolled patients – 117 with hypertension, 91 with diabetes, 51 had hyperlipidemia, and 92 had multiple diagnoses. Majority (86%) were Hispanic or white and 51% were female														
Intervention	Key elements of the CCM implemented: <table border="0" style="width: 100%;"> <thead> <tr> <th style="text-align: center;">Element</th> <th style="text-align: center;">Intervention Strategy</th> </tr> </thead> <tbody> <tr> <td>1. Information system</td> <td>enrollment in chronic disease registry</td> </tr> <tr> <td>2. Delivery system design</td> <td>evidence-based treatment algorithms telephone, email consultations</td> </tr> <tr> <td>3. Decision support</td> <td>volunteer MD and specialty support</td> </tr> <tr> <td>4. Self-management support</td> <td>collaborative goal setting, RN follow-up calls to monitor progress toward goal, patient education</td> </tr> <tr> <td>5. Community involvement</td> <td>volunteers from the lay and professional local community</td> </tr> <tr> <td>6. Health system leadership</td> <td>allocation of space and resources</td> </tr> </tbody> </table>	Element	Intervention Strategy	1. Information system	enrollment in chronic disease registry	2. Delivery system design	evidence-based treatment algorithms telephone, email consultations	3. Decision support	volunteer MD and specialty support	4. Self-management support	collaborative goal setting, RN follow-up calls to monitor progress toward goal, patient education	5. Community involvement	volunteers from the lay and professional local community	6. Health system leadership	allocation of space and resources
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6. Health system leadership	allocation of space and resources														
Outcomes	Primary efficacy endpoint was proportion of patients with clinically significant improvement in at least one of their chronic diseases. Disease-specific endpoints were a minimum one-stage reduction in BP for hypertensive patients, decrease of at least 1% of HbA1c for diabetic patients, reduction of risk group in LDL cholesterol for patients with hyperlipidemia Of the 109 patients completing the study, 79 showed a clinically significant improvement in at least one chronic disease. Of the 89 hypertensives completing the study, 57 (64%) improved at least one stage. For the 60 diabetics completing the study, 32 (53%) reduced their HgbA1c values at least 1%. For the 19 patients with elevated LDL cholesterol completing the study, 11 (58%) dropped one risk group. Attrition rates of over 40% are commonly reported in the delivery of chronic care to similar populations. In the present study, only 17% of patients dropped out (if we exclude those who acquired health insurance during the study)														
Limitations	Not a randomized, controlled trial; length of intervention varied greatly among patients, confounding data analysis and raising questions about sustainability of results; limited adaptation of community component of CCM														

A second study was uncovered, but implementation of the CCM was limited to only three of the six elements (see Table 2). The next section provides further details on the effectiveness of CCM components in various chronic conditions.

Table 2. Study Implementing and Evaluating Three CCM Elements									
Study	Implementing the Chronic Care Model for Improvements in Diabetes Care and Education in a Rural Primary Care Practice (Siminerio, Piatt & Zgibor, 2005)								
Methods	Prospective cohort study								
Participants	Six providers in a rural primary care practice and 29 patients with a confirmed diagnosis of type 2 diabetes. Seventeen patients completed the intervention – 65% were male, all were Caucasian, none had higher than high school education, all were insured								
Intervention	<p>Key elements of the CCM implemented:</p> <table border="0"> <thead> <tr> <th style="text-align: center;"><u>Element</u></th> <th style="text-align: center;"><u>Intervention Strategy</u></th> </tr> </thead> <tbody> <tr> <td>1. Decision support</td> <td>implementation of the ADA Standards of Care</td> </tr> <tr> <td>2. Self-management support</td> <td>patient education provided on-site by certified diabetes educator (CDE)</td> </tr> <tr> <td>3. Delivery system design</td> <td>“diabetes days” when CDE in office</td> </tr> </tbody> </table> <p>PROVIDER INTERVENTION: Received educational program that included review of ADA Standards of Care, relevance of standards and guideline adherence in the prevention of diabetes complications, and a discussion of diabetes self-management education (DSME)</p> <p>PATIENT INTERVENTION: Five 2-hour group sessions with 5-10 participants who met biweekly. DSME included following content areas: disease process, nutrition management (dietician provided MNT), physical activity, monitoring, medications, preventing, detecting, and treating acute complications, risk reduction in the prevention of chronic complications, psychological adjustment, goal setting and problem solving, preconception counseling/pregnancy care (if necessary); role of patient in supporting ADA provider adherence also discussed</p>	<u>Element</u>	<u>Intervention Strategy</u>	1. Decision support	implementation of the ADA Standards of Care	2. Self-management support	patient education provided on-site by certified diabetes educator (CDE)	3. Delivery system design	“diabetes days” when CDE in office
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1. Decision support	implementation of the ADA Standards of Care								
2. Self-management support	patient education provided on-site by certified diabetes educator (CDE)								
3. Delivery system design	“diabetes days” when CDE in office								
Outcomes	<p>Significant improvement in providers’ adherence to ADA practice guidelines</p> <p>Patients who received DSME had significant improvements in mean A1C values and HDLc levels from baseline to study end. Mean LDLc levels significantly worsened over the intervention as did proportion of subjects with LDLc levels =100mg/dL. No significant improvement in the proportion of subjects with BP values exceeding 130/80mm Hg. Improvements in all 3 empowerment subscales (psychosocial aspects of diabetes care, patient’s dissatisfaction and readiness to change, patient’s readiness to set and achieve diabetes-related goals), but not significant. Significant increase in diabetes knowledge following the intervention.</p>								
Limitations	Not a randomized, controlled trial; knowledge score improved, however, scores were relatively low from the start; although patients who received intervention improved in clinical and behavioral outcomes, small sample size of the patient intervention should be considered; small sample size diminished power to detect possible differences and likely led to nonsignificant results observed in the empowerment scales								

Evaluating Interventions Using Some Elements of the CCM

As indicated before, research to date has tended to focus on implementation of individual components of the CCM. Thus, it is worth examining exactly which elements have been proven effective in improving psychosocial as well as clinical outcomes in chronic disease patients. A literature search was conducted to identify studies of the effectiveness of interventions implementing one or more components of the CCM. The search was undertaken using PubMed (MEDLINE). Keywords used were *Chronic Care Model* and *evaluation* and articles were limited to those published in English that had an

abstract. Titles and abstracts were assessed to determine their relevance to the purpose of this review. Moreover, the bibliographies of these articles were examined to identify additional applicable studies.

In conducting our literature search on the topic at hand, we discovered that several leading experts in the area of chronic illness management have carried out systematic analyses of research evidence on the components of the CCM. For example, Bodenheimer and colleagues (2002b) performed an extensive review of studies of diabetes care programs applying at least one of the following components of the CCM: self-management support, decision support, delivery system design, and clinical information systems. In all, 39 studies were examined. The review produced several main findings, including:

- 32 of the 39 studies found that the intervention improved at least one process or outcome measure
- Five studies that included all 4 components mentioned above yielded improved patient outcomes. However, studies using fewer components were also effective.
- No specific element of the CCM was found to be critical for effectiveness. However, 19 of 20 interventions using a self-management component improved a process or outcome measure.
- Some studies focusing on specific chronic conditions (congestive heart failure, asthma, and diabetes) demonstrated that CCM interventions resulted in reduced health care costs and lower use of health care services.

Additionally, Bodenheimer (2003) examined the individual elements of the CCM to ascertain which of these, if any, are effective in improving patient outcomes. With regard to decision support, Bodenheimer cites several Cochrane reviews investigating the effect of different forms of physician education on professional practice and patient outcomes. They demonstrated that interactive educational workshops for physicians improved medical practice, whereas didactic presentations had almost no effect. In all 13 studies reviewed, face-to-face physician education improved medical practice. On the contrary, printed educational materials for physicians had no real impact on physicians' performance.

One type of clinical information system that has been commonly used are registries. According to Bodenheimer (2003), no studies specifically on the effect of registries appear in the literature. However, a Cochrane review of several diabetes trials found that information systems that identify at-risk patients and encourage health care institutions to engage them into care resulted in reduced HbA1c levels compared to patients in usual care.

The impact of physician feedback, another clinical information tool, has been less definitive. A review of studies examining physician feedback on a variety of conditions found that only 10 out of 24 studies demonstrated positive outcomes. The use of reminder prompts was also reviewed. Bodenheimer found that 22 of 26 studies on physician reminders noted improvements in physician performance. On the other hand, if overused in certain environments, reminders can turn counterproductive.

Interventions utilizing delivery system redesign primarily involved planned visits and case management. A planned visit is "an encounter, initiated by the practice or the patient, that focuses on overall patient goals and other aspects of care that are not usually delivered during an acute-care visit (American Academy of Family Physicians, June 2005)." The basic premise of a planned visit is to equip a patient with disease management tools based on certain clinical guidelines and the patient's personal needs. Planned visits can include some or all of the following: patient self-assessment, review of symptoms, reassessment of prescribed medications, physical exam, discussion of goal setting and an action plan, and scheduling of a follow-up appointment. Some studies have shown planned visits can have a positive impact on clinical outcomes, especially in diabetes patients. However, for patients with more complex situations planned visits did not fare so well when compared to usual care. For these patients case management may be more effective.

A review of six case management interventions in primary care settings for patients with a variety of chronic ailments found that all produced better outcomes compared to controls. While case management has proven to be a successful method in improving patient outcomes, it is very expensive and thus usually reserved for those at greatest risk. This point is addressed further in the latter sections of this report.

Lastly, because patients with chronic conditions are in direct control of most daily aspects of their disease management (e.g., exercise, diet, medication use, self-monitoring) self-management training and support is essential. Perhaps in recognition of this fact, more than any other component of the CCM, self-management support/training has received much attention in the published literature. Self-management education is not the same as patient education (see Table 3). Whereas the aim of traditional patient education is to provide disease-specific information and technical skills, self-management education

teaches skills for how to act on problems. Accordingly, self-management education complements the patient education approach to chronic disease management. Several reviews of studies of self-management interventions for various chronic conditions (e.g. diabetes, asthma, and arthritis) revealed that the inclusion of a problem-solving skills training leads to better clinical outcomes than providing patient education alone.

Table 3. Traditional Patient Education vs. Self-Management Education

(Bodenheimer et al., 2002)		
	Traditional Education	Self-Management Education
Content taught	Disease-specific information and technical skills	Problem-solving skills that can be applied to chronic conditions in general
Definition of the problem	Inadequate control of disease	Patient formulates the problem which may/may not be directly related to disease
Theoretical construct underlying the education	Disease-specific knowledge produces behavior change and leads to improved clinical outcomes	Patient's self-efficacy (learned through setting short-term action plans) leads to improved clinical outcomes
Goal	Compliance with behavior changes taught to patient to improve clinical outcomes	Increased self-efficacy to improve clinical outcomes
Educator	Health professional	Health professional or peer leader and other patients in the group

A literature search was undertaken to begin exploring the types of self-management studies that had been carried out targeting HIV/AIDS patients. As before, we used PubMed (MEDLINE) for our search. Keywords used were *self-management education, self-efficacy, and HIV/AIDS*. Table 4 outlines some of these interventions.

Table 4. Overview of Self-Management Interventions for PLWHA

Study	The Effectiveness of Self-Management Training for Individuals with HIV/AIDS (Inouye, Flannelly & Flannelly, 2001)
Model	Individualized self-management training
Methods	Randomization to intervention or control condition
Participants	Forty participants - intervention group (n=20), control group (n=20); 75% White and 90% male
Intervention	INTERVENTION: Administered individually twice a week for approx. 60-90 min. for 7 weeks. Program included biofeedback for relaxation; cognitive-behavioral management skills; anxiety, anger, and depression management; coping skills; psychoeducational classes CONTROL: received standard treatment of their primary care providers; at the end of the sessions they watched a video about nutrition and health related to HIV/AIDS, received wellness education, and were given related resources to take home
Outcomes	Intervention participants significantly improved in mood, specifically significant decreases in anger, confusion, tension, depression, and fatigue. Experimental group showed significant reduction in use of emotive, fatalistic, and palliative coping styles relative to controls and had significant reductions in their rating of effectiveness of confrontive, emotive, and fatalistic coping styles. Intervention participants reported significant increase on Chance scale and decrease on the Internal scale of the Health Attribution Test (HAT). Mean number of symptoms for two groups did not differ significantly. Similarly, no significant effect was found for CD4 counts.
Limitations	Small sample size diminished power for some analyses; nonrandom sample and measures/scales used restrict ability to generalize; considerable difference in contact time between the experimental and control groups (14 sessions ranging from 60-90 min. vs. 2 hrs.) may be a confounding factor

Study	Pilot Randomized Trial of Education to Improve Self-Management Skills of Men with Symptomatic HIV/AIDS (Gifford, Laurent, González, Chesney, & Lorig, 1998)
Model	Traditional patient education + self-care skills training
Purpose	To evaluate the acceptability, practicality, and short-term efficacy of a health education program to improve disease self-management in patients with symptomatic HIV/AIDS
Methods	Randomization to a seven-session group educational intervention or usual care control group
Participants	At baseline:34 participants in the intervention group and 37 in the usual care group. Fifty-eight (82%) subjects completed 3 month FUP and made up the analytic sample
Intervention	Positive Self-Management Program (PSMP) curriculum includes modules on how to: evaluate common sx's and decide about seeking care, use prescribed medications, make medication decisions and solve medication-related problems, improve communication with caregivers and health care providers, use cognitive-behavioral strategies and relaxation techniques for coping with sx's, exercise and set up a fitness program, eat well and prepare food in a healthy manner, make action plans and set personal goals
Outcomes	Primary outcome: symptom status Secondary outcomes: self-efficacy and health behaviors Number of severe symptoms decreased in intervention group and increased in the control group. No significant differences were found in pain, fatigue, depression, stress, anger, CD4 cell count measures between groups. Self-efficacy for controlling sx's increased in experimental group compared with a decrease in the control group. Trend toward more physical exercise in experimental group compared with controls and greater HIV/AIDS knowledge improvement seen in controls than experimental subjects
Limitations	Pilot study population exclusively male, mostly white and had high education level which may limit generalizability
Notes	Group classes conducted by trained peer leaders (1 of whom had HIV/AIDS) using PSMP manual; significantly immunocompromised sample – 72% had <200/mm ³ CD4 cells and 26% had 2 = AIDS-associated illnesses
Study	The impact of improved self-efficacy on HIV viral load and distress in culturally diverse women living with AIDS: The SMART/EST Women's Project (Ironson et al., 2005)
Model	Cognitive behavioral stress management training
Purpose	To examine if changes in self-efficacy in the context of a cognitive-behavioral intervention are related to changes in clinical (CD4, viral load) and psychological (depression, anxiety) indicators
Methods	Randomization to the cognitive behavioral stress management (CBSM) group intervention or the low intensity comparison condition
Participants	Fifty-six women over 18+ years old; majority of women (65%) were African American
Intervention	INTERVENTION CONDITION: Ten-week group expressive-supportive therapy program (90-minute CBSM and 30-minute relaxation component) which included didactic components explaining physiological effects of stress, CB interpretation of stress and emotions, identification of cognitive distortions and automatic thoughts, rational thought replacement, coping and assertiveness skills training, anger management, identification of social supports, combined with group processing of personal issues as conceptualized within CBSM framework COMPARISON CONDITION: Ten-weekly individual 2 hour sessions (45-minute educational videotape related to stress management/relaxation and coping with HIV/AIDS and a 75-minute entertainment tape)
Outcomes	Increases in AIDS self-efficacy was significantly correlated with increase in CD4 count and decreases in viral load over time but not associated with changes in either depression or anxiety. Increases in self-efficacy to medication adherence was related to decreases in log viral load. Increases in CB self-efficacy also associated with decrease in viral load, depression and anxiety but not with changes in CD4 count
Limitations	No significant differences between groups/no main effects of the intervention on self-efficacy were found in the present sample – (1) study restricted to a small sub-sample of

the larger study (the sub-sample that had CD4 cell counts and viral loads); (2) control group was really a low intensity intervention condition exposed to similar stress management information
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Integrating Self-Management into HIV/AIDS Care

The short list of articles outlined in Table 4 is evidence of the scarcity of literature that exists documenting implementation and evaluation of self-management in HIV/AIDS care. This is due in large part to the fact that with HIV/AIDS, traditionally other people, rather than the patients with the disease, have been responsible for most of the caretaking duties. In the epidemic's early years, AIDS patients were often hospitalized as they became sick and palliative care was the single model of care available. As years passed, widespread advancements to halt the disease progression effected a change from palliative care to case management-focused care (approximately 98 % of Title III and IV programs involve case management). While this reduced some of the burden on clinicians and auxiliary personnel providing intensive care to PLWHA, this shift did little to increase the autonomy of clients in terms of self-managing their disease. In fact, the tendency has been for case managers to gauge their success by how much patients depend on them instead of patients' self-reliance and ability to care for themselves. With the exception of the area of medication adherence, the concept of self-management has been by and large overlooked.

Given that many of the other CCM elements are already being implemented in CARE Act programs and initiatives and that case management, which is both costly and time intensive, is presently the most prevalent model of care, self-management seems like a worthwhile avenue to explore and begin to focus more of our efforts towards. The remainder of this report attempts to explain what an HIV/AIDS self-management education program might look like and how it could be implemented.

Recommendations and Future Directions

The following ideas and recommendations were generated from our literature review and from a series of conference calls that we conducted with leading clinicians in the area of HIV/AIDS care and management. Among the points discussed during these conference calls were:

- Elements of the CCM that could improve current HIV/AIDS care programs
- The interface between the CCM and quality improvement and quality management
- Utilization of the group visit model to disseminate self-management education
- Specific concepts that should be included in an HIV self-management curriculum
- Barriers or challenges to implementing an HIV/AIDS self-management program.

Merging Group Visits and Self-Management Education

An alternative to the traditional one patient, one physician office visit are group visits. The high productivity demands faced by physicians these days place considerable limits on patients' access to them which impacts patient education and outcomes. In contrast to the typical 15-minute visit, a two-hour group visit with 15-20 patients, all of whom have the same chronic illness, allows ample time for education and discussion. According to one pilot study of patients with poorly controlled type 2 diabetes who attended group visits, after one year a 32% reduction in total cholesterol/HDL ratios, a 30% reduction in HbA1c levels and a 7% decrease in health care expenses was noted (Masley, Sokoloff & Hawes, 2000). A two-year randomized clinical trial of 321 older patients with a chronic condition enrolled in Kaiser Permanente in Colorado found positive results in several areas as well. Compared to controls, group-visit participants had fewer emergency room visits, visits to subspecialists, repeat hospital admissions, phone calls to physicians (although more phone calls to nurses), and greater satisfaction with care (Beck, et al., 1997). All clinicians that we consulted agreed that the group visit is an ideal medium through which patient self-management concepts can be disseminated to PLWHA.

The fusion of self-management principles with the group visit type model is not a new one. Since the mid-1980s Kate Lorig, RN, DrPH and others at the Stanford Patient Education Research Center have been developing, implementing, and evaluating self-management programs for people living with a chronic disease. The Arthritis Self-Management Course (also known as the Arthritis Self-Help Workshop) was the first program implemented and became the prototype for subsequent self-management programs (general chronic disease, HIV, back pain, diabetes) offered both in English and Spanish and in-person and via the Internet. Self-management training takes place in small-group (8-15 people) workshops which are generally 6 weeks long, meet once a week for about 2 hours and are led by lay leaders, many with chronic conditions of their own, using a highly structured manual. Drawing on social cognitive theory, the programs emphasize increasing participants' self-efficacy or confidence in their ability to manage their illness and achieve their personal goals. In addition, the meetings are highly interactive, focusing on building skills, sharing experiences and support (Stanford Patient Education Research

Center, n.d.). At follow-up, program participants have shown significant improvements in their health status (fatigue, shortness of breath, pain, role function, depression, and health distress), health behavior (exercise, cognitive symptom management, and communication with physicians), and self-efficacy, as well as fewer emergency room visits compared to usual-care control subjects (Lorig, Ritter & González, 2003; Lorig, Sobel, Ritter, Laurent & Hobbs, 2001; Lorig et al., 2001; Lorig, González, & Ritter, 1999). Given these positive outcomes for other chronic conditions, this template can aid in the development of an HIV/AIDS self-management curriculum.

Self-management and Quality Management

As one of the components of the CCM, self-management is closely linked with efforts at improving quality management. The Institute of Medicine report entitled *Crossing the Quality Chasm: A New Health System for the 21st Century* acknowledged self-management education as an important facet of quality care (IOM, 2001). This is in accordance with HRSA/HAB's commitment to quality improvement as evidenced by their National Quality Improvement/Management Technical Assistance Center (NQC). In the context of quality management, group HIV/AIDS self-management programs could be implemented as a pilot study with empirical data determining degree of replication in primary care settings. For example, results may reveal that group self-management is more effective with women because they are traditionally more inclined to disclose and share information as compared to men. There is also a need to evaluate if group self-management leads to improvements in a variety of quality indicators (i.e., adherence, stress, depression, viral load, CD4 count) central to HIV/AIDS care.

HIV/AIDS Self-Management Curriculum

An HIV/AIDS self-management education program should be developed to provide education and skills training in a wide-range of areas pertinent to quality HIV/AIDS care. Possible program content is listed in Table 5.

Table 5. Content of an HIV/AIDS Self-Management Curriculum
Goal-setting and problem-solving strategies
Health literacy and HIV/AIDS-related knowledge
Navigating the health care system
Understanding the relationship between laboratory results and physical health
Managing negative emotions
Finding and building networks of social support
Strategies to increase medication adherence
Cognitive techniques for symptom management
Communicating effectively with your health care provider
Nutrition and exercise
Risk-Reduction strategies

Furthermore, health care providers are also in need of decision support and education so that they, too, can understand self-management principles and how to apply them in encounters with their patients. HRSA's AIDS Education and Training Centers (AETCs) are vehicles through which providers can receive this type of training.

Challenges to Implementing a HIV/AIDS Self-Management Program

Despite the potential value of self-management education, we recognize that there are challenges associated with its adoption, including:

- Clinician Buy-In

As one physician stated, "Many clinicians feel that healing is what happens when you are in a room with a patient. It's hard for some of us to give that up" (personal communication, August 1, 2005). Others agreed that clinician buy-in is one of the key challenges to effective implementation. Self-management is concerned with equipping patients with problem-solving skills so that they can accept responsibility to manage their own conditions with the support of their health care provider. Some clinicians, for various reasons, are hesitant about relinquishing some of their expertise and control of their patients' course of care and treatment. However, proponents of this concept believe that the ultimate goal should be a physician-patient collaborative in which physicians and patients make health care decisions together.

- Reimbursement for self-management education

Medicare, Medicaid, and most private health insurance companies do not reimburse for self-management education. The premise of CPT codes is a face-to-face one-on-one physician-patient encounter, which excludes the group setting. However, while there is still no standardized billing code for group visits, they are a billable service if a physician can clearly document that he/she performed a history and examination, reviewed a plan of treatment, or conducted medical decision making during the visit. One option is to assign a clinician to a group and he/she could examine each patient for a brief planned visit during the group meeting time.

- Disclosure of Positive Status in a Group Setting

The stigma associated with HIV/AIDS places a major psychological burden on patients. For some patients who decide to participate in a self-management program, it might be the first time that they have disclosed their positive status to other people. Thus, for many this may be a threatening factor that deters participation. The issue of confidentiality is especially concerning in a group setting.

Additional stigma associated with specific risk groups is also potentially challenging. However, patient education groups with mixed risk activities have been successfully implemented. A clinic that serves homeless people in Oakland, California is conducting these groups with hepatitis C patients undergoing treatment.

- Low Literacy

A 1993 National Adult Literacy Survey found that approximately

40 – 44 million Americans are functionally illiterate with an additional 50 million having only marginal literacy skills (Kirsch, Jungeblut, Jenkins & Kolstad, 1993). Ethnic minorities are over-represented among people with HIV and also have poorer (English-language) literacy rates compared to Whites (Kaestle, 2001). Self-management interventions must be adjusted to accommodate reading and comprehension skills of people with low literacy.

Conclusion

A major part of the CARE Act's mission is to improve the quality of care, and ultimately the quality of life, for PLWHA. We propose that the incorporation of self-management education into CARE Act activities would move us toward this goal by empowering patients to take a more proactive role in managing their illness. Moreover, HIV/AIDS self-management programs have the potential to serve as the foundation for a more effective and satisfying patient-provider partnership and to enhance the psychosocial and physical health of our clients.

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APPENDIX A. COMPREHENSIVE LITERATURE SEARCH OF ‘AGED’ PLWH/A FOR PHOENIX EMA NEEDS ASSESSMENT – March 2007

Categories

i. Biomedical	vi. Gay & Lesbian	xi. Nursing	xvi. Risk Assessment
ii. Case studies	vii. HIV & Chronic Illness	xii. Older Women	xvii. Service Models
iii. Clinical care	viii. Knowledge, Attitudes & Beliefs	xiii. Policy	xviii. Transmission/ Risk Factors
iv. Demographic/ Epidemiology	ix. Long Term Care	xiv. Prevention/ Education	xix. Other
v. Disease progression	x. Neurological	xv. Psychosocial	

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APPENDIX B. SURVEY INSTRUMENT

This survey is confidential, not anonymous. Individual responses will not be shared. The information you provide will be used to provide overall trend information. If you have any questions, please ask the survey facilitator.

1. What is your date of birth? _____
2. What is your Zip Code? _____
3. Are you HIV positive or has your HIV progressed to AIDS? HIV AIDS Don't Know
4. What Year were you diagnosed with HIV?: _____ unknown
5. What Year were you diagnosed with AIDS?: _____ unknown
6. Do you know how you may have acquired HIV/AIDS? (please check all that apply)

<input type="checkbox"/> Male sex w/male	<input type="checkbox"/> Injection Drug Use	<input type="checkbox"/> Health Care Worker
<input type="checkbox"/> Female sex w/female	<input type="checkbox"/> Sex with Drug User	<input type="checkbox"/> Mother w/HIV/AIDS
<input type="checkbox"/> Heterosexual Sex	<input type="checkbox"/> Sexual Assault	<input type="checkbox"/> Unknown
<input type="checkbox"/> Prison	<input type="checkbox"/> Transfusion	<input type="checkbox"/> Other
7. Do you currently have health insurance?
 Private Health Insurance (Humana, Aetna, etc) Medicare Medicaid (AHCCCS) VA None
 Delta Dental Other _____
8. When was the last time you saw a doctor to treat your HIV? _____
Month, Year
9. When was the last time you had a CD4 (T-cell) Count? _____
Month, Year
10. When was the last time you had a Viral Load test? _____
Month, Year
11. Are you currently taking ART (HIV) medications? Yes No Don't know
12. Have you ever been diagnosed with or treated for a mental illness? Yes No
13. Have you ever been diagnosed with or treated for substance abuse? Yes No
14. Have you ever been diagnosed with or treated for sexually transmitted diseases (STD)?
 Yes No Don't know RTA
15. Have you ever been diagnosed with or treated for diseases other than HIV?
 Yes No Don't know RTA
16. Are you now or have you ever been homeless? Never Currently homeless
 Been homeless in past 2 years, but not now
 Been homeless longer than past 2 years, but not now
17. Do you currently? Own your home Rent Live with a Friend/Relative Stay in a Shelter



Other _____

18. Do you get help with your rent? Yes No

19. Are you currently employed? Yes No

20. What is your approximate yearly income? \$0-\$9,999 \$10,000 - \$19,999 \$20,000-\$29,999
 \$30,000 - \$39,999 \$40,000-\$49,999 Over \$50,000

21. What is your highest level of education? Grade school Some high school High School degree/GED
 Some college College degree Some graduate school Graduate school degree

22. What is your sexual orientation? Gay Bisexual Straight Prefer not to Answer Other

23. Have you been in jail or prison in the past 6 months? Yes No

24. In what city and state were you FIRST diagnosed with HIV or AIDS? _____
city and state

25. Are you? Male Female Transgender Other _____

26. Do you consider yourself? African American American Indian Asian/Pacific Islander
 Caucasian Hispanic/Latino Multi-Racial
 Other _____

27. Who is your HIV Doctor? _____

28. What clinic/doctor's office do you go to for your HIV?
 Pueblo--Phoenix Pueblo--Scottsdale
 Sun Life Family Health Center VA McDowell Spectrum
 Health Unit (Prison) Other _____



29) **Need:** As a person living with HIV/AIDS, what are your 5 most important **needs**?

1. _____
2. _____
3. _____
4. _____
5. _____

30) **Use:** List the top 5 services that you **use** to stay in care for HIV

1. _____
2. _____
3. _____
4. _____
5. _____

31) **Barrier:** List the top 5 services that you **need** for HIV that are **hard to get**

1. _____
2. _____
3. _____
4. _____
5. _____

32) **Why are these services hard to get?**

33) List the top 5 services that you need for HIV that you **can't get**

1. _____
2. _____
3. _____
4. _____
5. _____

34) **Why can't you get these services?**

Thank you for your time in completing this survey. Your confidential responses will be valuable information for the Phoenix Area HIV Planning Council. If you would like information on how to participate with the Phoenix HIV Planning Council, please ask the survey facilitator.

IF YOU ARE 45 YEARS OR OLDER, PLEASE COMPLETE THE FOLLOWING PAGES.

THANK YOU!



35. Have you seen a dentist in the past year?
 Yes No

36. Have you had any teeth extracted in the past year?
 Yes No

36b) If yes, number of teeth extracted in past year:_____.

37. Have you had thrush in the past year?
 Yes No

37b) If yes, was it treated?
 Yes No

37c) Was treatment successful?
 Yes No

38. Have you ever had 'dry mouth'?
 Yes No

38b) If yes, how often?
 Once/day Once/week Ever

39. Have you ever had swelling of your neck or side of your face?
 Yes No

39b) If yes, before or after being told you are HIV+? Before After

40. Have you ever had sores in your mouth?
 Yes No

40b) If yes, before or after being told you are HIV+? Before After

OTHER DISEASES

41. Have you ever been diagnosed with any of the following?

- Cardiac/Heart
- High blood pressure
- Cancer (what kind? _____)
- Diabetes or metabolic problem
- Nerve (epilepsy, neuropathy)
- Hepatitis (what kind? A__ B__ C__)
- Tuberculosis
- Other (please list) _____

42. Have you had any of the following?

- Pneumonia
- Oral thrush
- Vaginal thrush
- Esophageal thrush
- Neuropathy (nerve tingling)
- Muscle wasting
- Lipodystrophy (body fat redeposited)
- Rashes
- Other (please list) _____

43. Were you diagnosed with these before or after your HIV diagnosis?
 Before After

44. Have any diseases other than HIV been caused by or worsened by HIV medications?
 Yes No

45. Do you take or did you ever take Hormone Replacement Therapy (HRT) to help with hot flashes/menopause?
 Yes-take HRT No-never took HRT
 Yes- once took HRT, not now

MENTAL HEALTH/SUBSTANCE ABUSE

46. Have you ever been told you have a mental health condition?
 Yes No

(IF NO, go to Question 49)

46b) IF YES, What condition(s)?
 Depression Mood/emotional problems
 Bipolar disorder Schizophrenia
 Other (please list)_____

46c) Was treatment ever recommended?
 Yes No

47. Have you **ever** had treatment for these conditions?
 Yes No

47b) IF YES:
a) Where did you get treatment?
b) When (Year) were you treated?
c) How long (Weeks, Months, Years)

48. Are you currently in treatment for these conditions?
 Yes No



49. Have you ever been told that you have cognitive (thinking) difficulty?

Yes No

49b) If YES, were you told this BEFORE or AFTER your HIV diagnosis?

Before After

49c) IF BEFORE, did this problem delay HIV testing or diagnosis?

Yes No

49d) IF AFTER, did they tell you if it was related to your HIV disease or medicine?

Yes No

50. Do you **currently use** substances?

Yes No

50b) IF SO, What kind?

Alcohol Cocaine Crystal meth Heroin Marijuana (grass)
 Other (please list_____)

51. Have you **ever injected drugs**?

Yes No

51b) IF SO, What kind?

Cocaine Crystal meth Heroin
 Speedball Other (list_____)

51c) IF SO, have you ever used a needle after someone else?

Yes No

51d) IF SO, did you clean the needle first?

Yes No

52. Have you ever given a used needle to someone?

Yes No

53. Have you ever shared drug paraphernalia?

Yes No

54. Have you ever shared drug paraphernalia in a shooting gallery?

Yes No

55. What do you use to clean syringes?

Bleach Water
 Alcohol Nothing

56. Do you **currently inject drugs**?

Yes No

56b) IF SO, What kind?

Cocaine Crystal meth Heroin
 Speedball Other (list_____)

56c) IF SO, do you share needles?

Yes No

56d) IF SO, do you clean needles?

Yes No

SEX PRACTICES

57. **Have you had sex in the past 6 months?**

Yes No

58. **How many sex partners have you had in the past 6 months?**

One 2-5 6-10 11-20 21-50
 > 50 RTA

59. In the past 6 months, during vaginal sex, how often did you use a condom?

Always Sometimes Never
 No vaginal sex

60. In the past 6 months, during anal sex, how often did you use a condom?

Always Sometimes Never
 No anal sex

61. Have you ever paid someone to have sex with you?

Yes No

62. Have you ever had sex with someone for money, drugs, rent or protection?

Yes No

63. Have you ever been the victim of domestic violence? Yes No

64. Have you ever been the victim of sexual assault? Yes No

65. Have you ever taken medicine to help your sexual performance?



(i.e. Viagra, Cialis, Levitra)

Yes No

65. Have you have sex without condoms since being diagnosed HIV positive?

Yes No

65b) YES, how often?

Always Sometimes Never

66. Why do you have unprotected sex?

- a) Feels good – better than when using condom
- b) Don't feel that I'm at risk
- c) Don't have time to use protection
- d) Partner won't let me use protection

67. Do you have sex with casual partners?

Yes No

68. Do you have sex with casual partners then have sex with your regular partner without disclosing the casual sex?

Yes No

68b) IF YES, how often?

Always Sometimes Never

68c) Are these casual partners?

Same sex Opposite sex
 Both

69. Did you think that you were not at risk for disease (HIV, STD) with sex?

Yes No

69b) Why or Why not?

Age Same partner
 Beyond menopause (women)

70. Do feel that you 'have to have' sex?

Yes No

70b) If yes, Why?

- Your age
- Being single
- Many women, not many men
- 'Made or forced to'
- Only way to connect
- Exchange sex-money, drugs, protection

71. Do you ever go on line to find sex partners?

Yes No

SEXUALLY TRANSMITTED DISEASES

72. Have you ever had a sexually transmitted disease?

Yes No

72b) What kind?

Syphilis Herpes Gonorrhea
 Chlamydia Genital Warts
 Trichimonas Other (list) _____

73. Have you had a sexually transmitted disease in the last year?

Yes No

73b) What kind?

Syphilis Herpes Gonorrhea
 Chlamydia Genital Warts
 Trichimonas Other (list) _____



APPENDIX C. POWERPOINT PRESENTATION OF FINDINGS